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# KENNEDY, ENZI, SNOWE CELEBRATE PASSAGE OF GENETIC INFORMATION NONDISCRIMINATION ACT

WASHINGTON, DC— Today, Senators Edward M. Kennedy, Chairman of the Health, Education, Labor and Pensions (HELP) Committee, Mike Enzi, Ranking Member of the HELP Committee, Olympia Snowe and released the following statements following the passage of the Genetic Information Nondiscrimination Act (GINA).

This legislation will prohibit genetic discrimination by health insurers and employers. The house is expected to take up identical language in the very near future.

Chairman Kennedy said, "This bill opens a new frontier in medicine in which we read the genetic make up of patients to stop diseases before they even happen. This legislation opens to door to modern medical progress for millions and millions of Americans. It means that people whose genetic profiles put them at risk of cancer and other serious conditions can get tested and seek treatment without fear of losing their privacy, their jobs and their health insurance. It's the first civil rights bill of the new century of the life sciences. With its passage, we take a quantum leap forward in preserving the value of new genetic technology and protecting the basic rights of every American."

Senator Enzi said, "This bill will help fulfill the promise of genetic research to save lives and reduce health care costs, by establishing basic protections that encourage individuals to take advantage of genetic screening, counseling, testing, and new therapies, without fearing that this information will be misused or abused. It protects both employees and employers by setting a standard of conduct that is easy to understand and easy to follow. We are far better off setting uniform, consistent rules of the road clearly and up front, rather than allowing them to be set piecemeal through litigation."

"Like race and gender bias, genetic discrimination is based on the unchangeable – yet it also requires a deliberate effort to obtain gene data in order to discriminate," said Senator Snowe. "The passage of GINA today represents the culmination of an effort that began more than ten years ago to put in place landmark protections to safeguard Americans against genetic discrimination."

A summary of the legislation is below.

#### THE GENETIC INFORMATION NONDISCRIMINATION ACT

Scientists have now completed the historic task of deciphering the entire DNA sequence of the human genetic code. This new knowledge is already allowing doctors to develop better ways to diagnose, prevent or treat some of the most feared diseases known to humanity. For genetic research to fulfill its promise to improve health, patients must be able to receive its benefits free from the fear that genetic information will be used as a basis for discrimination.

The bipartisan Genetic Information Nondiscrimination Act addresses these legitimate fears. This legislation will establish strong protections against discrimination based on genetic information in health insurance and employment. Support for the bill has come from a wide range of organizations representing patients, medical professionals, families and employees. We should give all Americans the comprehensive protections against genetic discrimination in health insurance and employment they deserve by enacting this important legislation.

### With regard to health insurance discrimination, the Act will:

- **PROHIBIT** enrollment restriction and premium adjustment on the basis of genetic information or genetic services;
- **PREVENT** health plans and insurers from requesting or requiring that an individual take a genetic test; and
- **COVER** all health insurance programs, including those under ERISA, state regulated plans, and the individual market.

## With regard to employment discrimination, the Act will:

- PROHIBIT discrimination on the basis of genetic information in hiring, compensation, and other personnel processes;
- **PROHIBIT** the collection of genetic information, and allow genetic testing only in very limited circumstances, such as monitoring the adverse effects of hazardous workplace exposures;
- **REQUIRE** genetic information possessed by employers to be confidentially maintained and disclosed only to the employee or under other tightly controlled circumstances.

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